End-of-Life Preferences in Hawaii

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Abstract

Questions on end-of-life preferences were included in two statewide, random-sample telephone surveys. Findings suggest that Hawaii residents are similar to mainlanders on their rates of advance directive completion, their preference for dying at home, their desire for hospice care when dying, and their support for legalization of aid in dying. Physicians are encouraged to ask these questions directly of their patients as a first step to improving end-of-life care.

Introduction

How many Hawaii residents have advance directives? What proportion prefers to die at home, rather than in a health care facility? How many are familiar with and would want to access hospice care at life's end? What proportion supports physician aid in dying? How many feel society's priority should be to improve care to the dying rather than to legalize physician-assisted suicide? These questions related to end-of-life care were asked through random-sample, population-based surveys of adults in Hawaii.

Literature Review

Increasing attention is being paid to issues of death and dying and the need to improve end-of-life care. This is not surprising, as the nature of death has changed considerably over the century. No longer are the majority of individuals dying from infectious diseases, in childbirth, in infancy, or in large-scale accidents. Rather, most residents will die of chronic, disabling conditions in very late life. The availability of life-prolonging technology, facilities, and drugs tend to push patients, families, and providers to "do everything" in the last year of life, even if the chance of recovery is slim and the chance of pain and reduced quality of life is great.[1]

Nationally, medical care at the end of life comprises roughly 12% of the total health care budget and 27% of the Medicare budget.[2] Existing data on hospice care suggest that it offers a cost savings over hospital care for individuals in the last 6 months of their lives.[2] However, in Hawaii only about 20% of deaths occur under hospice and many of these individuals are referred to hospice in the last weeks or days before death.[3] In these cases, there is little time to provide comprehensive palliative care measures that can help an individual have a good death and can help a family prepare for and recover from the death of a loved one. It is important to note, as well, that none of Hawaii's physicians and few of Hawaii's nurses are certified in palliative medicine. Limited physician training in end-of-life care is a nationwide problem, as major medical textbooks barely address end-of-life care.[4]

In part because of our ability to delay death and prolong life, the U.S. has become a "death-denying" society and issues of death and dying often are not discussed. In Hawaii, attitudes and practices relative to death and dying are influenced additionally by the different cultures that comprise our society. Qualitative research conducted in 1995-1996 found differences in attitudes toward planning for death among five Asian and Pacific Islander ethnic groups, which reflected respondents' varying cultural and religious traditions.[5] This work was followed in 1997 by interviews with 245 adults in five ethnic groups–Caucasian, Chinese, Filipino, Hawaiian, and Japanese–which also found ethnic differences in end-of-life preferences.[6] For example, in response to a question about physician-assisted suicide, only 33% of Filipino respondents and 51% of Hawaiian respondents said they felt there were conditions under which it should be allowed, compared to 74% of Caucasian, 77% of Chinese, and 90% of Japanese respondents.[7]

For several years, Hawaii has been looking at the "living and dying with dignity" issue and has taken steps to improve care provided to dying people. In 1999, Hawaii's efforts were boosted by a 3-year seed grant from the Robert Wood Johnson Foundation, which supports the work of a statewide coalition called *Kokua Mau,* comprised of about 150 agencies and individuals. The Coalition is focusing on several of the issues identified by the Governor's Blue Ribbon Panel on Living and Dying with Dignity in its 1998 report.[8] These include recommending appropriate changes to state policy, increasing access to spiritually and culturally acceptable care at the end of life, educating the public, and educating health practitioners. Leadership of the *Kokua Mau* Coalition rests in four agencies: the Executive Office on Aging, the U.H. Center on Aging, the Hawaiian Islands Hospice Organization, and the St. Francis International Center of Healthcare Ethics.

An important first step in improving care is to assess public knowledge, attitudes, and practices regarding end of life. Most of the previous studies on end-of-life preferences in Hawaii, however, have suffered from convenience sampling, i.e., participants were identified from senior centers, churches, and other organizations that attracted large numbers of individuals of these specific ethnic groups. Reported in this paper are findings from questions added to on-going surveys, which allowed the testing of four hypotheses.

Hypotheses

Hypothesis 1: Advance Directive Completion. The percentage of Hawaii residents with advance directives (living will and health care power of attorney) will be similar to or higher than rates found on the U.S. mainland.

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Justification. Advance directives are manifestations of the western concepts of autonomy, self-determination, and trust in legal systems, and cultural and religious traditions of Asian and Pacific Islanders may present barriers to advance directive completion.[9] In 1995-1996 focus groups conducted by the U.H. Center on Aging, some Native Hawaiian participants said that long-time distrust of the medical and legal systems presented a barrier to their signing documents, some Filipinos expressed a reluctance to do something that may "go against" God's plan for them, and some Chinese and Vietnamese participants (especially new immigrants) did not have advance directives because it was "bad luck" to talk about or plan for death.[5] In the 1997 study of 250 adults in five ethnic groups, however about 50% reported having advance directives.[6] In comparison, mainland studies suggest that advance directives have been completed by 10-25% of the general public.[10]

Hypothesis 2: Dying at Home. The majority of Hawaii residents would not want to die at home.
Justification. In work to improve end-of-life care, there is a common assumption that people would like to die at home rather than in a hospital or nursing home, and mainland survey data suggest that most Americans would prefer this.[11] But does this hold true in Hawaii? As learned in the 1995-1996 focus groups, a number of Asian and Pacific Islanders are from cultural traditions that believe in ghosts, karma, and a potential negative impact that an in-home death may have on the living and, possibly, on re-sale value of the home.[5]

Hypothesis 3: Desire for Hospice. The percentage of Hawaii residents who would want access to hospice services at life's end is similar the rates on the U.S. mainland.
Justification. In work to improve end-of-life care, there is a common assumption that people would like to avail themselves of hospice services (these can be provided in institutional and home settings). A similar question has not yet been asked of Hawaii residents. Local hospices report serving about 1,500 patients a year, representing about 19% of deaths, but estimate that two to three times as many dying individuals could benefit from hospice, and do not utilize it.[8,12] As reasons for low utilization could include lack of preference for hospice or lack of familiarity about hospice, our question on hospice probed for familiarity as well as preference.

Hypothesis 4: Legalizing Aid in Dying vs. Improving End-of-Life Care. Level of support for aid in dying among Hawaii residents is similar to that found on the U.S. mainland. When asked to choose between spending effort to legalize physician-assisted suicide vs. improving care to the dying, however, more Hawaii residents will choose the latter.
Justification. Mainland studies have found that 45-75% of respondents support physician- assisted suicide, however support among minority Americans runs 10-20 percentage points below support among Caucasians.[13-15] Compared to the mainland, support for aid in dying may be lower in Hawaii as the state is comprised mostly of non-Caucasians and because research suggests that some Asian and Pacific Islander cultures would oppose it. For example, members of the Catholic faith (including the majority of the 200,000 Hawaii residents of Filipino ancestry), do not condone suicide or euthanasia.[16] Other cultural traditions consider a suicide to be a "bad death" that might lead to bad consequences for surviving family members.[5] However, about 50% of the 245 adults who participated in our 1997 survey supported physician-assisted suicide, i.e., that a physician be allowed to provide a patient with the means to end his/her own life, such as a drug that can be lethal in certain doses.[7] Also, 67% of 419 residents polled in a 1998 telephone survey sponsored by the Honolulu Star-Bulletin favored "a law which would permit physician-assisted death under carefully controlled circumstances in Hawaii."[8]

There is growing recognition that people may support physician-assisted suicide because of the currently poor state of end-of-life care, which stems from attitudinal, behavioral, education, and economic barriers to providing appropriate, humane, and compassionate care for the dying.[17] Thus, the Robert Wood Johnson Foundation supported a survey that included this question: "In your opinion, how should we deal with the problem of end-of-life pain and suffering? Should our priorities be making physician-assisted suicide legal or improving care to the dying?" When asked to prioritize, 65% of respondents favored improving care to the dying while only 23% favored legalizing physician-assisted suicide.[18] We felt a similar split would be found among Hawaii residents.

Method

Design

Random-sample surveys increase the ability to generalize findings to the larger population and allow comparisons to studies in other locales. To test our four hypotheses, funding was secured from Hawaii Community Foundation for special analysis of relevant questions added to two existing surveys: 1) the 1998 Behavioral Risk Factor Surveillance System (BRFSS) sponsored by the Hawaii Department of Health and 2) a 1999 OmniTrak survey on health.

Data Sources and Analysis

1998 Behavioral Risk Factor Surveillance System (BRFSS). This telephone survey, sponsored by the U.S. Centers for Disease Control and conducted annually by the Hawaii Department of Health, gathers data from a random sample of Hawaii residents. In 1998, data were collected by telephone from 2,153 individuals age 18 and older. Characteristics of the sample are shown in Table 1. Once data collection was completed, the sample characteristics were compared with census distributions and the responses were weighted (adjusted) to reflect the population of the state, rather than of the sample. For example, in 1998 Caucasians were over-represented (comprising 37% of the sample, but only 22% of the state's population) while Native Hawaiians were under-represented (comprising 14% of the sample, but 21% of the state's population). The weighting procedure compensated for these and other discrepancies so that response rates to the survey questions could be generalized to the state as a whole. Following the weighting procedure, data were analyzed by gender, by age group, and by ethnicity. In the tables displaying findings from the BRFSS data (Tables 2, 3, 6, and 7), the "n" represents the actual number of individuals who gave a certain response. This is followed by the weighted percent, or the proportion that would have given this response if the sample accurately reflected the state's population.

Four questions related to end-of-life care were included that year:

Table 1.— Sample characteristics

	BRFSS n (%)	OmniTrak n (%)
Gender		
Male	933 (43)	321 (46)
Female	1,220 (57)	379 (54)
Age group		
18-24	159 (7)	123 (18)
25-44	901 (42)	275 (39)
45-64	714 (33)	204 (29)
65+	357 (17)	64 (9)
Unknown/refused	12 (<1)	34 (5)
Ethnicity		
Caucasian	803 (37)	242 (35)
Chinese	80 (4)	14 (2)
Filipino	232 (11)	67 (10)
Hawaiian	305 (14)	120 (17)
Japanese	475 (22)	90 (13)
Other	250 (12)	167 (24)
Unknown/refused	8 (<1)	
Education		
< HS	157 (7)	
HS grad	652 (30)	
Some college	607 (28)	
College grad	735 (34)	
Unknown/refused	2 (<1)	
Residence		
Oahu		400 (57)
Neighbor Island		300 (43)
Total	2,153 (100)	700 (100)

1) A living will is the written instructions you give about the kind of medical treatment you want or don't want. You fill it out before you fall ill so the doctors will know what you want if you ever get so sick you can't decide for yourself. Do you have a living will? (yes, no, unknown/refused); 2) A health care power of attorney is a written document that lets you designate someone else to make decisions regarding your health care if you get so sick that you can't decide for yourself. Do you have a health care power of attorney? (yes, no, unknown/refused); 3) Do you think a person has a moral right to end his/her life when faced with an incurable illness? (yes absolutely, perhaps depending on the circumstances, no, unknown/refused); and 4) Should doctors be allowed by law to end a patient's life by some painless method, if the ill person and his/her family requested it? (yes absolutely, perhaps depending on the circumstances, no, unknown/refused).

1999 OmniTrak Survey. In fall 1999, OmniTrak conducted a statewide, telephone survey of a stratified probability sample of adult residents; 700 individuals were included, 400 from the City and County of Honolulu and 100 from each of the other counties. Sample characteristics are shown in Table 1. These data were not weighted to correct for discrepancies between sample and population characteristics. Based on sample size and distribution, the sample error is ± 4% for the entire statewide sample of 700, ± 5% for Oahu's sample of 400, and ± 10% for neighbor island county samples of 100. Data were analyzed by gender, age group, ethnicity, and county.

The survey asked health-related questions and included three questions related to death and dying. These were: 1) Where would you want to be if you were dying? (home, hospital, nursing home, other, unknown/refused); 2) Regardless of what place you want to die, would you want hospice services? (yes, no, unfamiliar with hospice care, unknown/refused); and 3) In your opinion, how should we deal with the problem of end-of-life pain and suffering? Should our priorities be making physician-assisted suicide legal or improving care to the dying? (making physician-assisted suicide legal, improving care to the dying, unknown/refused). The first two questions were developed by the *Kokua Mau* team while the third question was identical to one included on a survey sponsored by the Robert Wood Johnson Foundation in March 1999.[18]

Findings

Advance Directives

Data from the BRFSS survey suggest that about 29% of Hawaii residents 18 and older have a living will (Table 2) and about 22% have a health care power of attorney (Table 3). These figures look comparable, if not at the high end, of rates found across the country (10-25%).[10] Rates of advance directive completion increased dramatically by age. In the 18-24 age group, only 5% had a living will and only 6% had a health care power of attorney. In the 65+ age group, however, 62% had a living will and 49% have a health care power of attorney. Our hypothesis, that the percentage of Hawaii residents with advance directives would be similar to or higher than rates found on the U.S. mainland, was supported.

Table 2.— Do you have a living will? (Source: BRFSS, N=2,153)

	Yes n (%)	No n (%)	Unk/Ref n (%)
Gender			
Male	277 (30)	647 (69)	9 (1)
Female	364 (27)	841 (71)	15 (2)
Age group			
18-24	7 (5)	151 (94)	1 (1)
25-44	151 (17)	742 (82)	8 (1)
45-64	244 (34)	465 (65)	5 (1)
65+	235 (62)	122 (35)	10 (3)
Unknown/refused	4 (30)	8 (70)	
Ethnicity			
Caucasian	279 (36)	520 (63)	4 (<1)
Chinese	25 (36)	55 (63)	
Filipino	32 (13)	199 (86)	1 (1)
Hawaiian	65 (22)	234 (77)	6 (1)
Japanese	177 (34)	288 (63)	10 (3)
Other	60 (23)	187 (76)	3 (2)
Unknown/refused	3 (29)	5 (71)	
Education			
< HS	52 (32)	103 (66)	2 (2)
HS grad	165 (25)	481 (74)	6 (1)
Some college	183 (27)	415 (72)	9 (1)
College grad	241 (34)	488 (65)	6 (1)
Unknown/refused		1 (50)	1 (50)
Total	641 (29)	1,488 (70)	24 (1)

Differences in advance directive completion rates, however, were seen by ethnicity, lending validity to our earlier findings from focus groups and structured interviews with convenience samples of Hawaii residents.[6] Specifically, significantly fewer individuals of Filipino and Hawaiian ancestry had living wills (13% and 22%, respectively) than did individuals of Japanese, Chinese, and Caucasian ancestry (33%, 36%, and 36%, respectively). Similar ethnic patterns were seen for the health care power of attorney. Interestingly, years of education did not seem to impact advance directive completion rates. Gender differences were not expected and were not found.

Table 3.— Do you have health care power of attorney? (Source: BRFSS, N=2,153)

	Yes n (%)	No n (%)	Unk/Ref n (%)
Gender			
Male	218 (23)	690 (75)	25 (2)
Female	283 (22)	897 (75)	40 (4)
Age group			
18-24	11 (6)	143 (92)	5 (2)
25-44	113 (13)	766 (85)	22 (2)
45-64	193 (27)	496 (69)	25 (4)
65+	182 (49)	173 (48)	12 (3)
Unknown/refused	2 (32)	9 (49)	1 (19)
Ethnicity			
Caucasian	234 (30)	545 (68)	24 (3)
Chinese	18 (27)	56 (67)	6 (6)
Filipino	23 (11)	203 (87)	6 (3)
Hawaiian	53 (20)	244 (77)	8 (3)
Japanese	125 (24)	331 (73)	19 (3)
Other	46 (18)	202 (82)	2 (1)
Unknown/refused	2 (26)	6 (74)	
Education			
< HS	46 (31)	110 (69)	1 (2)
HS grad	129 (19)	506 (78)	17 (3)
Some college	137 (20)	454 (78)	16 (2)
College grad	189 (26)	516 (70)	30 (4)
Unknown/refused		1 (50)	1 (50)
Total	501 (22)	1,587 (75)	65 (3)

Preferred Place of Death

Responses to the OmniTrak survey question, "Where would you want to be if you were dying?" are shown in Table 4. Of the 700 respondents, 65% said they would like to be at home and 8% would want to be in a hospital or nursing home. The last column in Table 6 combines individuals that named another place (12%) and those who said they didn't know or refused to answer (15%). Overall, the data suggest that fully two-thirds of Hawaii residents would prefer to die at home, disproving our hypothesis.

Some variations were seen by gender, age group, and ethnicity, however. More females than males reported preferring a home death, 74% vs. 59%. By age group, 71% of young and middle-aged adults (age 25-65) said they would want to be at home if they were dying, compared to about 60% of respondents in the younger and older age groups. Ethnically, preferences ranged from a low of 43% among Chinese to a high of 76% among Caucasian respondents.

Table 4.— Where would you like to be if you were dying? (Source: Omni Trak, N=700)

	Home n (%)	Facility n (%)	Unk/Ref n (%)
Gender			
Male	188 (59)	27 (8)	106 (33)
Female	280 (74)	24 (6)	75 (20)
Age group			
18-24	76 (62)	8 (6)	39 (32)
25-44	195 (71)	19 (7)	61 (22)
45-64	145 (71)	12 (6)	47 (23)
65+	37 (58)	11 (17)	16 (25)
Missing = 34 (5)			
Ethnicity			
Caucasian	184 (76)	14 (6)	44 (18)
Chinese	6 (43)	1 (7)	7 (50)
Filipino	36 (54)	10 (15)	21 (31)
Hawaiian	85 (71)	8 (7)	27 (22)
Japanese	61 (68)	10 (11)	19 (21)
Missing = 167 (24)			
Residence			
Oahu	258 (65)	32 (8)	110 (28)
Neighbor Island	210 (70)	19 (8)	71 (24)
Total	453 (65)	55 (8)	193 (27)

Table 5.— Regardless of what place you want to die, would you want hospice services? (Source: OmniTrak, N=700)

	Yes n (%)	No n (%)	Not farmiliar w/hospice n (%)
Gender			
Male	166 (52)	82 (26)	39 (12)
Female	261 (69)	76 (20)	15 (4)
Age group			
18-24	63 (51)	36 (29)	16 (13)
25-44	174 (63)	60 (22)	19 (7)
45-64	137 (67)	37 (18)	9 (4)
65+	36 (56)	15 (23)	6 (9)
Missing = 34 (5)			
Ethnicity			
Caucasian	158 (65)	46 (19)	13 (5)
Chinese	11 (79)	1 (7)	
Filipino	37 (55)	12 (18)	9 (13)
Hawaiian	73 (61)	37 (31)	5 (4)
Japanese	54 (60)	17 (19)	9 (10)
Missing = 167 (24)			
Residence			
Oahu	236 (59)	101 (25)	28 (7)
Neighbor Island	191 (64)	57 (19)	26 (9)
Total	420 (60)	161 (23)	55 (8)

Desire for Hospice

Shown in Table 5 are responses to the question, "Regardless of what place you want to die, would you want hospice services?" Fully 60% agreed, while 23% did not, supporting our hypothesis. Only 8% said they were unfamiliar with the concept of hospice care. The remainder of the sample, about 9%, did not know or refused to answer this question. The OmniTrak data suggest that more females would want hospice services than males, 69% and 52%, respectively. Almost 80% of the Chinese respondents said they would want hospice, compared to only 55% of Filipinos. Although inter-age-group differences were small, a greater proportion of individuals in the 45-64 age group said they would want hospice than in any other age group.

Legalizing Aid in Dying vs. Improving End-of-Life Care

Two questions were added to the BRFSS and one was added to the OmniTrak survey to explore these issues. As shown in Table 6, BRFSS data suggest that 64% of Hawaii residents unconditionally agreed that "a person has a moral right to end his/her life, when faced with an incurable illness." Another 9% responded "perhaps, depending on the circumstances." Only 17% said no. Also, 186 respondents, 8.4% of the sample, said they did not know or refused to answer this question (not shown in table). Responses to the question, "Should doctors be allowed by law to end a patient's life by some painless method, if the ill person and his/her family requested it?" are shown in Table 7. Similarly, 63% agreed unconditionally, 13% said "perhaps," 15% said no, and 193 (9%) said they did not know or refused to answer this question. As with other issues, however, variation in support was seen by ethnic group, with less support among Filipinos (45%) and Hawaiians (54%), and more support among Caucasians (70%), Chinese (71%), and Japanese (75%). This pattern of ethnic difference mirrors that found in our earlier structured interviews.[7] Small differences were seen by gender, age, and education, with greater support among males than females, in the 45-64 age group, and among those with more years of education.

The final question asked OmniTrak respondents, "In your opinion, how should we deal with the problem of end-of-life pain and suffering? Should our priorities be making physician-assisted suicide legal or improving care to the dying?" As shown in Table 8, when asked to choose between these two options, 52% thought priority should be given to improving care to the dying. Still, 28% preferred focusing priorities on legalizing physician-assisted suicide. Looking across ethnicities, the Filipino group stands out with the highest proportion in the "don't know/refused" group (27%) and the smallest proportion in the "legalize PAS" group (13%). Differences by age, gender, and Oahu/Neighbor Island residence were small. As Hawaii's overall response distributions on these questions are similar to those found on the mainland, the last hypothesis was supported.

Table 6.— Do you think that a person has a moral right to end his/her life, when faced with an inccurable illness? (Source: BRFSS, N=2,153)

	Yes n (%)	Perhaps n (%)	No n (%)
Gender			
Male	685 (67)	79 (9)	130 (16)
Female	751 (61)	114 (9)	235 (19)
Age group			
18-24	100 (60)	17 (10)	29 (19)
25-44	581 (64)	80 (9)	161 (18)
45-64	497 (70)	59 (8)	109 (15)
65+	222 (62)	36 (10)	65 (18)
Unknown/refused	9 (75)	1 (4)	1 (19)
Ethnicity			
Caucasian	572 (70)	69 (8)	118 (16)
Chinese	57 (71)	7 (7)	11 (17)
Filipino	107 (45)	19 (9)	68 (30)
Hawaiian	179 (54)	39 (16)	61 (18)
Japanese	355 (75)	38 (7)	45 (7)
Other	154 (59)	20 (7)	61 (26)
Unknown/refused	5 (67)	1 (15)	1 (9)
Education			
< HS	82 (57)	11 (5)	34 (19)
HS grad	400 (60)	64 (10)	133 (20)
Some college	412 (68)	56 (8)	92 (16)
College grad	513 (68)	62 (10)	106 (15)
Unknown/refused	2 (100)		
Total	1,409 (64)	193 (9)	365 (17)

Table 7.— Should doctors be allowed by law to end a patient's life by some painless method, if the ill person and his/her family requested it? (Source: BRFSS, N=2,153)

	Yes n (%)	Perhaps n (%)	No n (%)
Gender			
Male	637 (66)	96 (13)	133 (14)
Female	748 (61)	140 (13)	206 (17)
Age group			
18-24	109 (65)	11 (8)	28 (19)
25-44	570 (63)	100 (11)	153 (17)
45-64	477 (67)	78 (11)	102 (14)
65+	221 (60)	45 (14)	55 (15)
Unknown/refused	8 (66)	2 (14)	1 (19)
Ethnicity			
Caucasian	534 (65)	88 (13)	124 (15)
Chinese	57 (76)	6(6)	9 (12)
Filipino	109 (44)	28 (16)	60 (26)
Hawaiian	190 (57)	39 (17)	49 (16)
Japanese	336 (75)	45 (9)	46 (7)
Other	153 (63)	29 (10)	51 (21)
Unknown/refused	6 (76)	1 (16)	
Education			
< HS	82 (53)	17 (15)	30 (14)
HS grad	410 (61)	68 (11)	115 (19)
Some college	405 (87)	73 (15)	82 (12)
College grad	486 (65)	78 (11)	112 (15)
Unknown/refused	2 (100)		
Total	1,385 (63)	236 (13)	339 (15)

Table 8.— In your opinion, how should we deal with the problem of end-of-life pain and suffering? Should our priorities be a) making physician-assisted suicide legal? or b) improving care to the dying? (Source: Omni Trak, N=700)

	Legalize PAS n (%)	Improve care n (%)	Unk/Ref n (%)
Gender			
Male	97 (30)	158 (49)	66 (21)
Female	110 (29)	204 (54)	65 (17)
Age group			
18-24	29 (24)	61 (50)	33 (27)
25-44	87 (32)	145 (53)	43 (16)
45-64	67 (33)	107 (53)	30 (15)
65+	16 (25)	32 (50)	16 (25)
Missing = 34 (5)			
Ethnicity			
Caucasian	93 (38)	113 (47)	36 (15)
Chinese	4 (29)	8 (57)	2 (14)
Filipino	9 (13)	40 (60)	18 (27)
Hawaiian	31 (26)	66 (55)	23 (19)
Japanese	29 (32)	41 (46)	20 (22)
Missing = 167 (24)			
Residence			
Oahu	111 (28)	211 (53)	78 (20)
Neighbor Island	96 (32)	151 (50)	53 (18)
Total	198 (28)	362 (52)	139 (20)

Discussion

On the whole, it appears that Hawaii residents are similar to mainlanders on their rates of AD completion, their preference for being at home at life's end, their desire for hospice services when dying, and their support for the legalization of aid in dying.

That 29% of the general population and 62% of the 65+ age group reported having a living will is quite impressive, suggesting that advance directive completion rates in Hawaii are on the high end of the range of estimates found in mainland studies. These figures reflect well on our local medical facilities that are required under the Patient Self Determination Act to provide information about advance directives. Also to be thanked are local programs, such as the U.H. Elder Law Program, and individuals, such as estate planning lawyers, that help individuals complete such documents. Recent legislative action resulted in the passage of a new advance directive law that consolidated older statutes on the living will, health care power of attorney, and organ donation under the Uniform Health Care Decisions Act 169 of 1999.[19] Many health care facilities are developing new forms, although an older living will document is still valid if it includes indication of nutrition/hydration preferences, as is the older durable power of attorney document. Under the new law, statutory damages for non-compliance with an individual's advance directive are $500 or actual damages plus attorney fees.[19]

Although the majority of Hawaii residents and other Americans state a preference for dying at home, in fact most deaths occur in facilities. In Hawaii, 63% of the 7,712 deaths in 1997 occurred in hospitals and only 21% occurred in the home.[20] Other studies offer several explanations for this discrepancy. First, while the majority of well adults may think they want to die at home, the proportion of terminally ill patients who desire a home death is probably less than 50% and the proportion of terminally ill patients who actually die at home is probably less than 30%.[21-22] Research suggests that desire for a hospital death is higher among terminally ill patients with small or over-burdened family.[21-22] The factor that most accounts for variance across states in place of death, however, is not related to patients or families. Rather, the risk of in-hospital death is higher for residents of regions with greater hospital bed availability and use.[11,23-24]

That 60% knew about and would want hospice services at life's end is gratifying, but this figure is much higher that the actual proportion who are dying under hospice care at this time. For example, of the 7,712 deaths in 1997, only 1,196 (15%) were attended by hospice at time of death. While rates increased to about 19% in 1999, it is estimated that two to three times as many dying individuals could benefit from hospice.[8,12] Recognizing that not all dying individuals are appropriate for hospice care and applying recommended referral criteria to the state's 1999 deaths, local hospices feel that they are only serving about half of appropriate cancer deaths, 10% of appropriate cardiac deaths, and 15% of appropriate chronic obstructive pulmonary disease deaths.[3,12]

Even more startling, the median length of stay in hospice seems to have decreased in the past few years, from about 40 days in 1997 to about 20 days in the first quarter of 2000.[3] A short length of stay in hospice decreases the opportunity to provide comprehensive palliative care measures that can help an individual have a good death and can help a family prepare for and recover from the death of a loved one. Physicians should increase their familiarity with hospice services and inform families of the benefits of hospice care at life's end. Applauded is the U.H. John A. Burns School of Medicine, which requires first-year students to train as hospice volunteers and continues to add didactic and practical training related to end-of-life care to its 4-year curriculum.[25]

Hawaii's major ethnic groups register different levels of support for aid in dying, with greater support seen among Chinese, Japanese, and Caucasian residents and less support seen among Filipino and Hawaiian residents. On average, however, 64% of Hawaii residents support a person's moral right to end his/her life when faced with an incurable illness and 63% feel that doctors should be allowed by law to end a patient's life by some painless method if the ill person and his/her family requests it. When forced to choose whether to focus on legalizing physician-assisted suicide or improving end-of-life care, more Hawaii residents said to focus on improving end-of-life care (52% vs. 28%).

Although not asked in either Hawaii survey, it is interesting to note that the mainland survey from which this question was taken also asked about respondents' impressions of the quality of end-of-life care. Very few felt that the current medical care system did an excellent job caring for dying patients and almost 50% said it did a poor or fair job in helping patients to remain pain-free.[18] Clinical policy for care at the end-of-life is being advanced through the development and promulgation of Core Principles for End-of-Life Care which, by 1999, had been adopted in full or part by the American Medical Association,13 subspecialty societies, and the Joint Commission for the Accreditation of Healthcare Organiza-

tions (JCAHO) (Table 9).[26] Physicians are encouraged to contact their professional societies to learn more about specific recommendations for their subspecialty. JCAHO attention should work to improve hospital practices related to end-of-life care as well.

Table 9.— Core Principles for End-of-Life Care[26]

Clinical policy of care at the end of life and the professional practice it guides should:

1. Respect the dignity of both patient and caregivers;
2. Be sensitive to and respectful of the patient's and family's wishes;
3. Use the most appropriate measures that are consistent with patient choices;
4. Encompass alleviation of pain and other physical symptoms;
5. Assess and manage psychological, social, and spiritual/religious problems;
6. Offer continuity (the patient should be able to continue to be cared for, if so desired, by his/her primary care and specialist providers);
7. Provide access to any therapy which may realistically be expected to improve the patient's quality of life, including alternative or nontraditional treatments;
8. Provide access to palliative care and hospice care;
9. Respect the right to refuse treatment;
10. Respect the physician's professional responsibility to discontinue some treatments when appropriate, with consideration for both patient and family preferences;
11. Promote clinical and evidence-based research on providing care at the end of life.

Limitations

A random-sample survey is the preferred method for gathering data on public opinion. Still, this method has its limitations. For example, individuals who participate in telephone surveys must have phones, must be home when the pollster calls, must answer the telephone (surveyors hang up without leaving a message if they reach an answering machine), and must have the time and willingness to answer the survey questions. Thus, the final survey sample might not reflect true population demographics. While the BRFSS applies a weighting procedure to correct for this, most surveys, including the OmniTrak survey, do not. In the latter, only 14 individuals of Chinese heritage participated, enlarging the margin of error around estimates for this group. Still, it is validating that the same age/ethnic variances in advance directive completion and PAS support were similar in this population-based survey and the earlier convenience-sample studies.

Conclusion

This study provides physicians with additional information about Hawaii resident preferences at the end of life. As public attention and consumer awareness about end-of-life issues increase, it is imperative that healthcare systems encourage physicians and patients to discuss options and preferences. Research suggests that outpatients want their doctors to initiate discussions about advance planning, and that these discussions should occur after their physician-patient relationship is established but while the patient is still well.[10] Conversations should address values and expectations related to life prolongation, proxy decision making, preference of place of death, potential benefits of hospice, and so forth.[27] These conversations take time, and providers and insurers must develop mechanisms that will allow these conversations to take place.[27]

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